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Identifying Factors Underlying the Decision for Genetic Carrier Screening Among Women in Montgomery County

Scholarly Project Final Report

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Literature Review

As medical scientific technologies evolve, numerous medical tests help not only physicians with their clinical judgment, but also patients by empowering them with more knowledge of their own health. An example is Genetic Carrier Screening (GCS) [1-2].

Genetic Carrier Screening (GCS) is a genetic test that allows patients to find out if they carry genes for certain genetic disorders. The results of the test enable patients to make changes to their family planning decisions and prenatal care when appropriate and allow them the opportunity to seek further medical and social support [3]. The clinical utility of GCS is evident in the significant decrease in the number of Tay-Sachs disease incidences between 1970 and 2000 (a 90% decrease) and decreases in the number of newborns born with cystic fibrosis and thalassemia since the development of GCS in 1970s [4-7].

Despite these health benefits and notable clinical utility of GCS, GCS has not been utilized in most nations due to moral and ethical controversy among the public [8-12]. Certain populations have shown to have positive attitudes toward GCS, such as those who have a higher risk of having severe recessive disorders. African Americans, for example, are supportive of sickle cell carrier screening [13-15]. Also, the majority of cystic fibrosis patients and their family members support the practice of GCS [16-19]. However, others fear that GCS might result in unnecessary feelings of guilt and a greater burden to parents [17].

Other factors have been shown to be associated with attitudes and intentions towards GCS, even within at risk populations. One study demonstrated that among African American patients, their socio-demographic factors (age, education), previous screening knowledge, and the presence of perceived threat were associated with the patient's intention to undergo GCS for sickle cell trait screening [20]. In cystic fibrosis patients, other studies have shown that socioeconomic status, ethnicity and sex affected patients' decisions to accept GCS [21-27].

There are limited studies that address factors that affect the decision-making process of the general public for GCS. One study examined the impression and attitudes about preconception GCS among 468 OB-GYN female patients in Montgomery County, OH. The study showed that although patients believed that it would be beneficial to know their carrier status and that it is their responsibility to undergo testing, they did not want to go through GCS [28]. That study did not investigate the socioeconomic and demographic factors that may have impacted the decision to choose GCS among this population. Therefore, the objective of this study is to describe socioeconomic and demographic factors affecting these female patients' desire to undergo GCS.

Hypothesis/Specific Aims/Research Questions

This paper explores the socioeconomic and demographic factor differences between patients who desire to undergo GCS and patients who do not desire to undergo GCS, and their respective correlations.

Socioeconomic factors that will be examined in this study are types of medical insurance and highest level of education. Demographic factors include age and religious affiliation.

I hypothesize that patients with higher education (some college and beyond) and private insurance are more willing to undergo GCS. In regards to the demographic factors, I hypothesize that older patients are more willing to go through GCS and that patients with religious beliefs are less likely to undergo GCS.

Methodology

Context

This is a secondary data analysis of the data collected in the study that examined attitudes of 468 OB-GYN female patients in Montgomery County, OH toward GCS [28]. Data for the OB-GYN patients in Montgomery County study was collected via an anonymous survey distributed to 468 patients attending OB/GYN visits at Wright State Physicians and at Five Rivers Center for Women's Health from July 2015 to August 2016. Survey respondents included patients who are currently pregnant, and those considering future fertility or currently undergoing fertility treatment. Participants were over 18 years old and able to understand and write in English. All responses were collected via convenience sampling of a self-administered survey containing a front page with consent information. The final sample for analysis was 468 women.

Data Collection

A descriptive self-administered survey composed of 31 questions was distributed to the subjects, who completed and returned the survey at the physician's office. The questionnaire was designed to gauge participants' attitudes and perspectives regarding GCS with both closed and open-ended questions. The survey questions include patient demographics (age, gender, ethnicity and religious preferences), socioeconomics (highest level of education and type of health insurance), and questions to measure patient opinions on GCS (positive or negative attitudes towards GCS, desire to undergo GCS, and how much a patient would be willing to pay to have GCS, etc.) For my study, I will focus on associations between patients' age, religious affiliation, highest level of education, type of health insurance, and their desire to go through GCS.

The independent variables of interest include socioeconomic factors such as highest level of education and type of health insurance and demographic factors such as patients' age and religious affiliation. Patients' education levels were subdivided into the following three categories: high school/GED, some college, and graduate school/doctorate level. They were also classified on the basis of religious affiliation.

Religious affiliation was classified into Christian, Judaism, Islam, Buddhism, Hinduism, Jehovah's Witness, no religious affiliation and other. For the purpose of this study, I will simply classify religion as "religiously affiliated" and "no religious affiliation." Type of health insurance that the individuals have were recorded as "Private," "Medicaid," and "Self-pay/none." Participants' age was measured as a continuous variable in which they simply answered with a number. However, I will divide the variable into three age groups, namely, 18-28, 29-36, and 37+.

The dependent variable is individuals' desire to go through GCS. Participants were asked to answer the question, "Do you desire to undergo Genetic Carrier Screening?" with "Yes" and "No" as answer choices.

No power analysis was done because my study is a secondary data analysis. Therefore, the available data set is predetermined.

Data Analysis

This is a retrospective quantitative analysis of existing survey data. Socioeconomic and demographic factors that I analyze are different types of categorical data; nominal categorical data: religious affiliation and type of health insurance; ordinal categorical data: highest level of education; continuous data: age.

Considering categorical independent and dependent outcomes and the purpose of the study, which is looking for correlations between the two, I am going to utilize Chi-Square testing to analyze the data. Statistical analysis will be conducted using IBM version 24.0 Statistical Package for the Social Sciences software (SPSS) with a p-value of 0.05.

Data cleaning was previously completed to confirm that there were no data entry errors. To prevent any risk of bias, missing data will be excluded from the analysis. Therefore, the sample size might fluctuate due to the lack of response.

Results

Demographics

Four hundred sixty-eight patients participated in the survey. This study focused on female patients only. Table 1 presents the demographics of the survey respondents. These participants were categorized into three groups: 64.1% (n=300) undergoing general gynecologic care, 22.4% (n=105) currently pregnant, and 13.5% (n=63) considering or receiving fertility treatments. The mean age was 30.03 ± 6.98 years with a range of 18-63. The three groups were similar in age (see Table 1). The majority of women were Caucasian (77.4%; see Table 1).

Table 1 Patient demographics and distribution (N=468)

Demographic	Proportion/Mean
Patient type [% (n)]	
General gynecology	64.1% (300)
Currently pregnant	22.4% (105)
Considering or receiving fertility treatment	13.5% (63)
Average Age for Patient Type (mean \pm SD)	
General gynecology	30.21 \pm 7.65
Currently pregnant	28.51 \pm 5.05
Considering or receiving fertility treatment	31.67 \pm 5.89
Gender	
Female	100% (468)
Ethnicity	
Caucasian	77.4% (362)
African American	16.2% (76)
Caucasian-African American	0.6% (3)
Asian-Hispanic	1.3% (6)
Pacific Islander	0.2% (1)
Other	4.3% (20)

Patients' desire to undergo GCS based on socioeconomic and demographic factors

A greater number of patients in every age group did not desire to have GCS, compared to patients who did desire to have GCS. Of those in the 18-28 age group, 43.6% (n=65) desired to undergo GCS while 56.4% (n=84) did not. For the 29-36 age group, 36.8% (n=57) desired to undergo GCS while 63.2% (n=98) did not. Among those whose age is greater than or equal to 37, even a greater proportion of patients 73.0% (n=46) did not wish to have GCS while only 27.0% (n=17) wished to have GCS. No significant relationship between patients' age and their willingness to go through GCS was found (P=ns) (See Table 2).

Similarly, a greater number of patients responded that they would not like to undergo GCS, compared to the number of patients who did desire GCS, no matter what their insurance type was. Among those with private insurance, 36.2% (n=100) wished to go through GCS while 63.8% (n=176) did not. Of those with Medicaid 41.4% (n=36) desired GCS while 58.6% (n=51) did not. Self-pay patients were split in half in terms of their desire to go through GCS. Again, there was no significant relationship between respondents' type of insurance and their desire to undergo GCS (P=ns) (See Table 2).

Participants' highest level of education did not affect their desire to have GCS (P=ns). Of those whose highest level of education was high school or GED, 38.6% (n=27) desired to undergo GCS while 61.4% (n=43) did not. Among participants whose highest level of education was some college, 36.6% (n=59) desired to go through the test while 63.4% (n=102) did not. Lastly, of patients whose highest level of education was graduate school or doctorate level, 40.0% (n=42) wished to go through GCS while the rest, 60.0% (n=63) did not wish to undergo GCS (See Table 2).

Participants' religious affiliation had a significant relationship with their desire to undergo GCS (P<0.05). Of those who are not religiously affiliated, 45.3% (n=53) answered that they desired the test while 54.7% (n=64) replied that they did not. However, among those who are religiously affiliated, 34.1% (n=86) desired to have the test while a significantly greater number of patients 65.9% (n=166) did not (See Table 2). Religiously affiliated patients were more likely to refuse GCS.

Table 2 Patients’ desire to undergo GCS based on age, type of insurance, education level, and religious affiliation

	Desire to Undergo GCS		<i>P</i>
	Yes	No	
Age [% (n)]			<0.07
18-28	43.6% (65)	56.4% (84)	
29-36	36.8% (57)	63.2% (98)	
37+	27.0% (17)	73.0% (46)	
Type of Insurance [% (n)]			<0.575
Private	36.2% (100)	63.8% (176)	
Medicaid	41.4% (36)	58.6% (51)	
Self Pay/None	50.0% (3)	50.0% (3)	
Education [% (n)]			<0.86
High School/GED	38.6% (27)	61.4% (43)	
Some College	36.6% (59)	63.4% (102)	
Graduate School/Doctorate Level	40.0% (42)	60.0% (63)	
Religiously Affiliated [% (n)]			<0.04
No	45.3% (53)	54.7% (64)	
Yes	34.1% (86)	65.9% (166)	

Patients’ desire to undergo GCS based on previous pregnancy history

Following analysis of the relationship between socioeconomic and demographic factors and desire to undergo GCS, previous pregnancy history was identified as another potential factor affecting patients’ desire to undertake GCS. Hence, a closer look at the relationship between participants’ previous pregnancy history and their willingness to go through GCS was performed. Those who desired to undergo GCS had a lower number of pregnancies and number of living children than those who did not desire to undergo GCS, but the groups were similar for number of miscarriages and elective abortions (see Table 3).

In addition, those who had a previous abnormal ultrasound or abnormal prenatal testing were not more likely to report that they desired to undergo GCS (see Table 4).

Table 3 Descriptive statistics of participants' pregnancy history

	Desire	N	Mean	Std. Deviation	P
Number of Pregnancies	Yes	140	1.24	1.644	<0.001
	No	237	1.84	1.775	
Number of Miscarriages	Yes	139	0.36	0.780	<0.82
	No	234	0.38	1.099	
Number of Elective Abortion	Yes	136	0.12	0.405	<0.99
	No	231	0.12	0.437	
Number of Living Children	Yes	138	0.64	1.139	<0.001
	No	235	1.11	1.160	

Table 4 Patients' desire to undergo GCS based on history of abnormal ultrasound and prenatal screening in a previous pregnancy

	Desire to Undergo GCS		P
Abnormal Ultrasound [% (n)]	Yes	No	<0.10
Yes	41.2% (7)	58.8% (10)	
No	37.7% (126)	62.3% (208)	
Abnormal Prenatal Screening [% (n)]	Yes	No	<0.35
Yes	53.8% (7)	46.2% (6)	
No	37.6% (126)	62.4% (209)	

Participants' attitudes toward GCS

The majority of patients reported a positive or neutral attitude toward GCS; only nine patients had negative attitude toward GCS (See Table 5). However, interestingly, a

larger number of participants did not wish to have GCS for every sub-group that was examined.

Table 5 Participant’s attitudes toward GCS (N=466)

Attitudes toward GCS [% (n)]			
Positive	Negative	Neutral	Unsure
45.9% (214)	1.9% (9)	47.6% (222)	4.5% (21)

Currently pregnant patients’ desire to undergo GCS

We further explored the subgroup of “Currently pregnant” patients’ responses to determine whether “currently pregnant” patients might have a greater interest in learning about their fetus’ health and potential genetic disorders. “Currently pregnant” patients’ age, type of insurance, and religious affiliation did not have a significant association with their desire to go through GCS (see Table 6). H highest level of education was significantly related to their wish to undergo GCS with women having a higher level of education being less likely to desire GCS ($p < 0.05$).

Table 6 Desire to undergo GCS based on age, type of insurance, education level, and religious affiliation (N=82) among women who were currently pregnant

	Desire to Undergo GCS		<i>P</i>
	Yes	No	
Age [% (n)]			<0.66
18-28	28.1% (9)	71.9% (23)	
29-36	23.4% (11)	76.6% (36)	
37+	50.0% (1)	50.0% (4)	
Type of Insurance [% (n)]			<0.28
Private	21.7% (13)	78.3% (47)	
Medicaid	38.1% (8)	61.9% (13)	
Self Pay/None	0.0% (0)	100.0% (1)	

Education [% (n)]			<0.05
High School/GED	46.7% (7)	53.3% (8)	
Some College	12.9% (4)	87.1% (27)	
Graduate School/Doctorate Level	27.6% (8)	72.4% (21)	
Religiously Affiliated [% (n)]			<0.77
No	27.6% (8)	72.4% (21)	
Yes	24.5% (13)	75.5% (40)	

Discussion

We found there was no difference in the desire to undergo GCS related to age, type of insurance, or highest level of education. However, when only currently pregnant women were examined, those with at least some college were less likely to desire to undergo GCS than women with high school as their highest level of education. Previous studies have shown that patients with higher education tend to worry more about the possibility of eugenics and the use of new biotechnology in medicine than others [29-30]. However, numerous studies have shown that high socioeconomic status with higher educational level and income are associated with a greater acceptance of GCS [31-36]. Additionally, studies show that women with higher education are more favorable toward abortion compared to other women when they are at risk of sacrificing their career [37]. This study shows that women who reported having a religious affiliation were less likely to desire GCS than women reporting no religious affiliation. Previous studies support that religiously affiliated patients, no matter of their affiliated religion or ethnicity, do not consider terminating the pregnancy as an option in case of an affected child because of their faith [28-40]. This is not surprising because religions have a quite consolidated view on preserving and protecting life. And patients with religious beliefs are more likely to have a bigger support system that can certainly help them emotionally and spiritually [41-43].

Another study shows that even though a majority of Lutheran pastors believe that genetic counseling is beneficial and like to be involved in the decision-making process of family planning, they do not regard abortion as an option for the fetus with Huntington disease and Down syndrome [44]. However, many of the patients agree that termination

may be allowed in case of legal issues such as rapes are involved or when the mother's life is in danger [38].

The positive correlation between educational attainment and religious services attendance might explain the unwillingness of patients with a higher education and religious belief to go through GCS [45]. Also, patients with higher level of education are more likely to have more means to raise children with special needs.

Women with fewer pregnancies and fewer living children are more likely to desire GCS. There have been studies that found the same: patients with fewer or no children are more likely to undertake GCS out of uncertainty and worry about their pregnancy [34,46]. Having previous abnormal ultrasound or prenatal testing did not change their desire to have GCS compared to those without this history. There is no study to explain this finding, and this undermines the idea of the perceived threat that will be discussed later.

The majority of women reported a positive or neutral attitude toward GCS, however, their desire to undertake GCS was low.

This inconsistency between patients' attitudes and behavior toward GCS seems to be common among patients. [8,12, 47-49]. It can be possibly explained by patients' perceived threat. The perceived threat is a measure of how much risk an individual believes that he or she might have a trait for genetic diseases. If a patient has direct or distant family members with genetically transmitted health conditions, his or her perceived threat is likely to be higher compared to others with no family history of inheritable illnesses. How much they know about the severities and consequences of those diseases might affect their perceived threat as well. Patients with a greater perceived threat are more likely to agree to have GCS for both inheritable and other nonheritable disorders [20,28]. On the other hand, patients with low perceived threat would be less willing to have GCS even if they do not necessarily have negative opinions regarding GCS.

Participants' perceived norm might be another explanation for the discrepancy observed between their attitudes and behavior [28,50-52]. Perceived norm is the perceived social pressure to perform or not to perform certain behaviors [52]. Respondents are likely to be aware of the controversy over GCS due to ethical and moral

responsibilities. Just being aware of this negative connotation and impression about GCS is likely to affect patients' decision when it comes to undergoing GCS. Even though patients might not have negative opinions on GCS, they might be concerned of being judged by their family members, friends, or even general public to undergo GCS.

Lastly, respondents' fear that GCS might result in unnecessary feelings of guilt and a greater amount of burden to them as parents might prevent them from taking GCS [17]. Patients and their partners, who do not wish to live with the distress sprung from the knowledge of their carrier status, support the "right to not know." They believe that if nothing can be altered about their carrier status, knowing their carrier status would result in a tremendous amount of anxiety and stress with no solution to it [48-49].

Limitations

The study has several limitations. This was a secondary analysis of existing data with a questionnaire developed previously for another study. The questionnaire does not include ways to measure content validity or internal consistency. However, the question that measures participant's desire to go through GCS was clearly worded as "Do you desire to undergo Genetic Carrier Screening?" with "Yes" and "No." Therefore, it meets face validity.

The data were collected via self-report of a convenience sample, and most participants identified themselves as Caucasian females with Christian faith living in Ohio. Therefore, the data might include respondent bias and be difficult to apply to the general population. This study was a cross-sectional study in which analysis of causation or changes over an extended length of time would not be applicable. Lastly, employment status or income of participant could have assessed their socioeconomic status but were not included in this study.

We examined patients' pregnancy history and its relationship with willingness to undergo GCS. In addition, there could be different variables (i.e. ethnicity, cultural norms) that this study did not examine but may influence participants' desire to have GCS. Investigating these other confounding variables would be the next step in further

exploring the utility of GCS. Exploring association of respondents' perceived threat and norm and their decision regarding GCS will be able to provide further and deeper understanding of this study's results.

Conclusion

Awareness of the association between religious belief and desire to undergo GCS can help physicians prepare for conversations with patients about GCS. While education level was not associated with the desire to undergo GCS in the overall group of patients, women who were currently pregnant were less likely to desire GCS with increasing levels of education. Few patients had a negative attitude toward GCS, although attitudes toward GCS were not related to reported desire to undergo GCS. Future research may include examination of the relationship of other factors, such as medical history, pregnancy history, and cultural norms, and GCS. Understanding the influence of other factors on the desire for GCS is important not only to reconcile the gap between benefits and patient use of GCS but also to build stronger patient-physician rapport.

Appendix A Patient Survey

THIS SURVEY ASKS QUESTIONS THAT MAY BE SENSITIVE IN NATURE. THESE QUESTIONS ARE THEORETICAL, AND ITS INTENTION IS NOT TO OFFEND OR IMPLY THAT GENETIC CARRIER SCREENING WILL BE USED IN THIS WAY.

WE ARE INTERESTED IN SEEKING YOUR OPINION ABOUT THE POTENTIAL WAYS THAT THIS TYPE OF SCREENING COULD BE USED IN THE FUTURE. YOU CAN RESPOND TO AS FEW, OR AS MANY QUESTIONS AS YOU WOULD LIKE TO.

BY COMPLETING THE SURVEY, YOU ARE CONSENTING TO PARTICIPATION IN THIS RESEARCH. WE WILL NOT HAVE ANY WAY OF IDENTIFYING YOU BASED ON THE ANSWERS YOU GIVE TO THE SURVEY. THE DATA COLLECTED FROM THIS RESEARCH WILL NOT BE USED TO IMPLEMENT POLICY THAT WILL ALTER INSURANCE COVERAGE. IF YOU HAVE ANY QUESTIONS REGARDING THE SURVEY, PLEASE TEAR OFF THE BACK PAGE WHERE YOU WILL FIND CONTACT INFORMATION FOR THE INVESTIGATORS CONDUCTING THIS RESEARCH.

Please answer all questions to the best of your ability.

NOTE: definitions are provided for medical terms. All defined terms are **bolded**.

The end of the survey has all definitions listed in alphabetical order.

Full Disclosure: There are some sensitive topics covered in this study including abortion. The Researchers conducting this study do not support any specific viewpoints (positive or negative) regarding this or other sensitive topics.

1. Age: _____

2. Gender: Female Male

3. Ethnic group: Caucasian African American Asian Hispanic Pacific Islander Other:

4. Education: High School GED Some College Graduate school Doctoral degree
 Other: _____

5. Geographic location:
Please specify State: _____

6. Type of medical insurance: Private Medicaid Self Pay/none

7. Religious preference: Catholicism Protestantism Judaism Islam Buddhism Hinduism
 No religious affiliation Other: _____

8. Please provide numbers for your pregnancy history.
number of pregnancies: _____ (regardless of outcome, and include current)
number of **miscarriages**? _____
number of elective **abortions**? _____
number of living children: _____

9. Are you currently pregnant? Yes No

10. Do you currently use contraception?
 Yes No If yes, what type? _____

11. Please select the category that most closely defines your current reproductive status.
 Sexually active with no intention of having a child in the near future
 Sexually active, willfully not using contraception, but uncertain about wanting to have a child in the near future or wishing to leave it to chance
 Sexually active, with a partner whom I know I cannot produce a child with. For example, you are both the same sex or one or both of you cannot have children.
 Sexually active with the intention of having a child in the near future

12. Were you aware of **Genetic Carrier Screening** prior to your appointment today?
 Yes No Unsure why?: _____

13. If you answered yes to #12, please select the source from which you received this information.
 commercial media (TV, computer, billboards, etc.)
 OB/GYN
 genetics counselor

- fertility doctor
- other, please specify _____

14. Did you understand the material provided to you prior to this survey?

- Yes No Unsure why?: _____

15. After reading the material, do you desire to undergo **Genetic Carrier Screening**?

- Yes No Unsure why?: _____

16. If you are a **genetic carrier** for a disease, what would you choose to do next? Please select one option.

- Would have my partner screened
- Nothing, would not change plans
- Would choose to undergo **In Vitro Fertilization (IVF)**
- Would only choose **prenatal screening** in pregnancy
- Other (Please specify): _____

17. Have you had a history of any of the following? Please answer Yes/No.

More than 2 miscarriages

- Yes No Unsure why?: _____

Child with a genetic disease/disorder?

- Yes (if yes, please specify what disease/disorder) _____
- No Unsure why?: _____

Abnormal ultrasound in a previous pregnancy?

- Yes No Unsure why?: _____

Abnormal Prenatal Screening (Quad screen, First Trimester screen, Non invasive prenatal screening) in a previous pregnancy?

- Yes No Unsure why?: _____

Amniocentesis or Chorionic Villi Sampling (CVS) in a previous pregnancy?

- Yes No Unsure why?: _____

18. Generally, how do you feel about **genetic carrier screening**?

- Positive
- Negative

- Neutral
- Unsure why?: _____

19. Which of the following providers do you feel could adequately counsel you on the risks and benefits of **genetic carrier screening** and explain the results of the test? Please select all that apply.

- Primary OB doctor
- High risk OB doctor
- Reproductive Endocrinologist doctor
- Family Practice doctor
- Genetics counselor
- Nurse midwife
- Nurse Practitioner
- I am not interested in being counseled by anyone
- Other (Please Specify): _____

20. Considering your medical history and family history, do you feel **genetic carrier screening** should be performed before any other testing?

- Yes No Unsure,
- If yes, please explain why.: _____

21. Do you feel that **genetic carrier screening** should be available to all fertility patients, defined as women undergoing treatment with assisted reproductive technologies?

- Yes No Unsure why?: _____

22. Do you feel that insurance should cover **genetic carrier screening** to women undergoing treatment with assisted reproductive technologies?

- Yes No Unsure why?: _____

23. Do you feel that **genetic carrier screening** should be offered to all pregnant women?

- Yes No Unsure why?: _____

24. Do you feel that **genetic carrier screening** should be offered to all women of reproductive age regardless of whether they are actively trying to conceive?

- Yes No Unsure why?: _____

25. Which potential traits would you be interested in testing for by **genetic carrier screening** if they became available? Please check all that apply.

- Inheritable disease (for example, cystic fibrosis or sickle cell)
- Autism
- Complex disease, such as diabetes or lupus
- Psychiatric conditions, such as depression or schizophrenia
- Adult-onset inheritable disease, such as breast or colon cancer
- Personality disorders, such as obsessive-compulsive disorder or oppositional defiant disorder
- I would not be interested in any of these options

26. Do you feel that doctors have a moral obligation to support limits on the **genetic carrier screening** that is available to you?

- Yes No Unsure

Please explain your answer.

27. Considering cost, when would you do **genetic carrier screening**? Check all that apply.

- if your insurance covered the testing?
- if insurance required a **copay**
- if insurance did not cover the testing

28. How much would you be willing to pay for **genetic carrier screening** as insurance does not currently cover the test?

- I would not pay out of pocket
- \$50-100
- \$150-250
- \$300-500
- \$>500

29. What would lead you to have an abortion? Please check all that apply.

- I would NEVER get an elective **abortion**
- Diagnosed with fetal condition where survival is unlikely
- Diagnosed with severe fetal anomalies but survival is likely with severe disability
- Diagnosed with minor fetal anomalies and survival is likely with minor disability

Unsure what I would do

Other (please

explain); _____

30. Please select which of the following statements more closely describes how you feel.

I feel that finding out the results of a genetic test that could reveal I have a chance of passing on a disease to a child such as cancer, heart disease, diabetes, other major illnesses or genetic diseases would cause me to worry excessively and be a greater burden than not knowing.

I feel that it would be more beneficial to know the chance I have to pass on an illness to a child so I can try to prevent future children from having disease.

31. Please select which of the following statements more closely describes how you feel

A potential mother has a responsibility to do everything in her power to make certain her child does not suffer; this includes any genetic testing available to screen for potential illness.

Regardless of the potential outcome for the offspring, the ability for the mother to choose to have genetic testing or not is more important. Without this ability, the mother is viewed as less important than the potential child she will have.

Definitions

Abortion: The act of choosing to end a pregnancy, during the first 28 weeks.

Amniocentesis: A test your OB/GYN does between 14-16 weeks of pregnancy to detect an abnormal baby, such as one with Down Syndrome.

Chorionic Villi Sampling (CVS): A test your OB/GYN does between weeks 10-12 of pregnancy to detect an abnormal baby, such as one with Down Syndrome.

Copay: A payment agreement where the patient pays a certain amount and the insurance company pays the rest of the amount.

Genetic carrier: Someone who has a risk of passing a genetic abnormality to their children as determined by testing.

Genetic Carrier Screening: A test you can have before becoming pregnant to determine your chances of having an abnormal baby due to a genetic problem.

In Vitro Fertilization (IVF): A procedure that involves a fertility doctor who can harvest your eggs, fertilize them with sperm outside of your body, then put one or more of them back into your body to help you have a child.

Miscarriage: This occurs when a baby dies early in pregnancy (before the 20th week).

Prenatal Screening: Testing done once you are already pregnant to determine if the baby has any specific abnormalities including Down Syndrome.

Ultrasound: A medical instrument that the OB/GYN places on your tummy to look at your developing baby.

Quad Screen: A test your OB/GYN does between weeks 15-20 of pregnancy that can detect an abnormal baby, such as one with Down Syndrome or with an abnormal spine.

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